

Integration: The Experience of Living with Insulin Dependent (Type 1) Diabetes Mellitus

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Dans la présente étude théorique à base empirique, c'est à partir de l'analyse d'entrevues et de données écrites de douze adultes diabétiques insulino-dépendants que l'on a examiné ce que signifie vivre avec l'insulino-dépendance. On y décrit la théorie à base empirique de l'intégration : l'intégration de l'être en tant que personne et celle de l'être en tant que diabétique. L'intégration est un processus en trois étapes : le fait d'être diabétique, le point tournant et la connaissance que l'on a de la maladie (science of one). Les gens qui étaient dans la phase de connaissance de la maladie étaient devenus des experts en diabète et bien qu'ils n'adhéraient pas au régime de vie que préconisaient les spécialistes de la santé, ils contrôlaient bien leur glycémie. Chacun avait mis en place un style de vie qui facilitait ou entravait le processus d'intégration. La présente théorie de l'intégration indique la nécessité de changements importants dans la relation malade-infirmière, et dans l'information que l'on peut donner sur le diabète.

In this grounded theory study, the experience of living with insulin dependent diabetes emerged through analysis of interview and written data from 12 adults with the condition. The grounded theory of integration – the integration of the personal and the diabetic selves – that emerged is described. Integration is a three-phase process: having diabetes, the turning point, and the science of one. Those in the science of one phase had become experts in their diabetes and, although they did not adhere to the regimen prescribed by health professionals, they were in good glycemic control. Each person developed lifeways that facilitated or inhibited the integration process. This theory of integration suggests a need for significant changes in client-nurse relationships and diabetes education.

Diabetes mellitus is a chronic disease that results from an absolute or relative lack of insulin or its physiologic function (Cahill, 1985). The earliest known descriptions of diabetes date from about 1500 B.C. (Cahill), but the focus on treatment did not begin until the 1900s (Etzwiler, 1984). Current treatment involves educating clients about diabetes, prescribing a treatment regimen (diabetes regimen), and motivating clients to adhere to this regimen, because health professionals believe adherence leads to glycemic control (Hernandez, 1994), which is, in turn, necessary

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for the prevention of complications (Diabetes Control & Complications Trial Research Group, 1993).

Previous research has focused on predicting or promoting adherence through the use of a variety of theories, strategies, and techniques recommended by health professionals. In contrast, this grounded theory study describes the participants' view of diabetes – the experience of living with insulin dependent diabetes mellitus (IDDM) and the metaphors of integration that characterize this phenomenon.

Background

Diabetes affects about 4% to 6% of the population in Canada (Expert Committee of the Canadian Diabetes Advisory Board, 1992). Approximately 16 million people in the United States have diabetes (American Diabetes Association, 1996).

The impact of diabetes on the individual is significant, because it causes major disruptions in lifestyle and functional health and results in increased morbidity and mortality. In current approaches to treatment, designed to counteract these potential consequences, the emphasis is placed on educating the person with diabetes about the disease and the diabetes regimen it entails. Education programs are designed to help clients normalize blood glucose levels, thereby reducing complications. Metabolic (glycemic) control is considered the ultimate outcome for clients with diabetes (Brown, 1990), but adherence is regarded as an important goal of education programs (Mazze, 1986) because it is believed that adherence to a diabetes regimen is necessary for glycemic control (Alogna, 1980; Becker & Janz, 1985; Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Geller & Butler, 1981; Jenny, 1984; Rosenstock, 1985; Tillotson & Smith, 1996). Therefore, much of the diabetes educator's energy is devoted to diabetes control issues – presenting information to clients in a manner that promotes adherence, or structuring the practice situation in a way that facilitates adherence (Hernandez, 1991).

Despite the efforts of educators, adherence has been an elusive goal (Kurtz, 1990; Rosenstock, 1985; Schlenk & Hart, 1984), and investigators have not detected a relationship between adherence to the prescribed regimen and glycemic control (Glasgow, McCaul, & Schafer, 1987; McCaul, Glasgow, & Schafer, 1987; Polly, 1992; Watkins, Williams, Martin, Hogan, & Anderson, 1967; Williams, Martin, Hogan, Watkins, & Ellis, 1967; Wooldridge, Wallston, Graber, Brown, & Davidson, 1992). In addition, the results of diabetes simulation exercises undertaken by

nurses and other health professionals indicate that even they could not adhere to a diabetes regimen, in spite of the short period of the simulation (Warren-Boulton, Auslander, & Gettinger, 1982; Welborn & Duncan, 1980). The inability of the adherence framework to explain the experience of living with diabetes verifies the need for an alternative understanding of what it is to live with diabetes.

Diabetes practitioners have failed to recognize the contradictory role that conventional practice and the diabetes research and theoretical literature have promoted for those with diabetes. On the one hand, educators encourage clients to take charge of their diabetes (Feste, 1992; Funnell et al., 1991); on the other hand, education programs promote acquiescence to the diabetes regimen, the verbal and/or written instructions of the diabetes educator/team. This inconsistency is illustrated in an article in which the purpose of education was identified as the process of enabling clients to make informed choices about their diabetes self-care, but educators were told to measure client adherence to understand their difficulties adhering to the regimen (Anderson, Fitzgerald, & Oh, 1993). It is not known how individuals with diabetes perceive and handle this conflicting role demand. The literature reflects the health professional's view of diabetes. Omitted is a description of what it is to live with diabetes, the perspective uncovered in this research.

When the researcher began this study, there were no reports of investigations into the experience of diabetes from the perspective of the client. A few researchers have begun to focus on selected aspects of diabetes, using in-depth interviews with clients to obtain information about their perspective. These studies demonstrate how individuals with diabetes perceive the impact of their diabetes (Oram, 1992), how they undertake self-care management decisions (Nichol, 1990; Paterson & Sloan, 1994; Price, 1993), or focus on the problems of living with diabetes (Maclean & Oram, 1988) or its complications (Ternulf Nyhlin, 1990). The literature is devoid of reports on the overall experience of living with diabetes.

The research question of the current study was framed as "What is the experience of living with insulin dependent diabetes as described by adults who have it?" The goal was to generate a theory to account for the pattern of behaviour that is relevant and problematic for those with IDDM. The study began with the interviewing of four participants over a two-year period (Hernandez, 1991), with subsequent theoretical sampling over a three-year period. The educational implications of the findings have been published elsewhere (Hernandez, 1995b).

Method

The method of inquiry was grounded theory methodology (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987), in which the data have been systematically analyzed in such a way that the emerging theory results from the continuous interplay between analysis and data collection (Strauss & Corbin, 1994). Other important features of grounded theory are theoretical sampling, data collection guided by emerging theory, and write-up of theoretical ideas – as they emerge – in memo form. This method was selected because it offers the researcher a fresh perspective of a familiar situation (Stern, 1980). Prior to undertaking this study, the researcher had been involved in diabetes education for 10 years and was entrenched in the adherence framework (the professional view), whereas grounded theory methodology allowed me to view diabetes from the perspective of the person with diabetes. A combination of semi-structured interviews and writing tasks was used to facilitate accuracy and completeness of the interpretations.

Sample

Twelve participants were recruited with the assistance of endocrinologists and nurses and through self-referral. Participants were adults over the age of 21 with IDDM. The first participants, two males and two females, were between the ages of 24 and 39, in good glycemic control as judged by glycated hemoglobin, and not health professionals. Over a three-year period, eight more participants were recruited, the selection of whom was based on emerging theory, which guided the choice of participants to be interviewed next. For example, the first four participants all had good glycemic control; therefore, to determine the impact of level of glycemic control on the emerging theory of integration, the next participant had to be in poor glycemic control; then two health professionals with good glycemic control were recruited; later, two participants over age 50, with diabetes for 35 or more years, were interviewed; finally, three participants from a different geographic location were included in the study.

Procedure

An ethical review of the study was completed by the University of Toronto. The researcher conducted all interviews except those of the last

three participants, who were interviewed by a master's prepared nurse, in another location. The participants were initially contacted by phone and an appointment was made for the first meeting. Each person was seen on three or more occasions. The purpose of the first interview was to ensure that study criteria were met, to explain the purpose of the study, to choose a fictitious name that would be used in all interviews, and to obtain written, informed consent. The fictitious names were chosen by the participants and were used in all audiotapes and written data.

At the second meeting, participants were interviewed for about one and a half hours in their homes. The interviews were audiotaped and transcribed verbatim. Interview questions were open-ended to facilitate elaboration and to capture the participants' experiences and feelings. Twelve open-ended questions were developed for this study and were used only if the participants did not offer any of the desired information. These 12 questions had been reviewed by an experienced grounded theory researcher and revised based on that review. The initial interview question was "I want to get some idea of what the experience of living with diabetes has been like for you, from the beginning and up to the present. Could you talk about that for me?"

At the end of the first interview, the writing tasks (a diabetes paper and a diabetes journal) were described and notebooks were provided. The diabetes paper presented an opportunity for participants to tell their personal stories. No firm guidelines were provided for the paper, but it was designed to gain an understanding of what it is like to have diabetes, from the perspective of the writer. The journal was to be an ongoing record of the participant's thoughts relative to diabetes. Participants were asked to keep this journal for a minimum of three days. The writing tasks were completed by the first four participants but were optional for the subsequent eight, because these tasks were thought to limit the type of participant who could be included in the study. Of the eight, three completed both paper and diary, four handed in the diary only, and the remaining participant performed neither task.

The final interview lasted one to two hours and was held from six months to one year after the initial one. This interview took place after all writing tasks had been handed in and analyzed. Its purpose was to validate the researcher's interpretation of the data or to ask further questions that had been prompted by the data analysis. Additional interviews were held at the request of some participants.

Data Analysis

Data collected through the interviews, diabetes paper, and diabetes journal were analyzed using the constant comparative or grounded theory method (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987). Interview data and written data were constantly compared for similarities and differences and patterns of relationships. Line-by-line scrutiny of the data generated substantive in vivo codes such as "being like others," "being like a regular person," and "not being different," reflecting the substance of what the participants said, often in their exact words. As these codes were sorted and compared, they were clustered into larger categories – for example, the above in vivo codes were collapsed into a category labelled "being normal." This intensive analysis "sparked" many memos. Memos were useful in reducing the number of categories, providing leads as to where to go next with the interviews or the theoretical sampling, and identifying hunches or sources of discord as the theory was developed. They were essential to writing up the findings. As linkages between categories were discovered, they were collapsed into general categories. Three major conceptual categories were identified, which together described the Basic Social Process (BSP). The BSP met the BSP criterion of accounting for the changes and adjustments that occurred over time following diabetes diagnosis.

Results

Integration was the BSP underlying the experience of insulin dependent diabetes: having diabetes, the turning point, and the science of one. This theory of integration will be described and participants' comments will be used to illustrate key aspects.

The experience of living with IDDM was a three-phase process of integration: having diabetes, the turning point, and the science of one. Integration is defined as "an ongoing process in which the two selves (diabetic and personal) more fully merge to create an individual who is healthy, both mentally and physically. This unification of the selves is manifested in the person's ways of thinking, being and acting (including verbalization)" (Hernandez, 1995a, p. 19). The *personal self* is the person as he or she existed prior to the diagnosis of diabetes. The *diabetic self* is the new entity that emerged and had to be contended with upon diagnosis. A metaphoric theme seemed to permeate each story, including the language used to tell the story. These themes were labelled *metaphors of integration*, because they demonstrated the orientation of the participants toward their diabetes and toward life, and

they represented the process of living in which the *diabetic self* and the *personal self* have become integrated. However, those in the having diabetes phase had passive metaphors that reflected minimal integration and hindered the integration process.

Two internal conflicts began in the having diabetes phase: *Who owns diabetes?* and *To tell or not to tell?* These conflicts could be resolved in any of the phases. For those in the having diabetes phase much of the *ownership of diabetes* was still in the domain of the health professionals, but for those in the science of one phase the person with diabetes had taken ownership. In the having diabetes phase, participants focused more on following the rules (diabetes regimen) set by health professionals; failure (inadequate glycemic control) was attributed to their own inability to follow the rules. During the turning point, there was more involvement with the diabetes and with decision-making. In the science of one phase, the individual had taken ownership of the diabetes and the decisions related to all aspects of the disease. Health professionals were used to seek updates about research findings or new products, or to vet ideas. However, the ultimate decisions were made by the individual with diabetes. Mike made the analogy that when you are first diagnosed you become like a child again and want the diabetes educator to tell you what to do. Later, "You go into maturity. You start making the decisions for yourself." Mike believed this transference of ownership should also hold true for children with diabetes, because "even children have a feeling for their own bodies." Sarah's attitude was more poignant, "If I want to ruin my life, I will ruin my life. If I want to make my life be good, I will make it be good."

Deciding *whether to tell* another that one had diabetes was a major source of internal conflict. Resolution can take years, and even those in the science of one phase limit the number of their confidantes based on the perception of a need to know or a threshold of intimacy in a relationship. Telling does not necessarily occur in a verbal exchange, as Bridget demonstrated in one of her journal entries:

I was sitting in class and realized I hadn't taken my insulin. I didn't want to do it there because of who was sitting beside me. I wasn't sure how he would take it if he saw me using my Novo-Pen.

Richard showed that he was comfortable with revealing his diabetes in some situations, and in some ways, but not in others:

I would say that's one area that I have certainly changed. I never used to – I used to try and hide the fact that I was a diabetic. But now whenever I travel with anybody at all, I always make a point of telling him right off the bat, "I am diabetic." It makes so much sense, and yet

before, as I say, I was probably embarrassed and didn't want to talk about it.

I've got a diabetic colleague. He'll sit there in a meeting and just get his pen [insulin injection device] out and roll his sleeve up and do an injection in front of everybody sitting there. No inhibitions at all. I don't feel comfortable doing that.

Phase One: Having Diabetes

The first phase of the theory of integration, *having diabetes*, began with diagnosis. It was characterized by a lack of knowledge or fragmented, unconnected pieces of knowledge. During this phase the person with diabetes may exhibit lack of interest in or denial of the diabetes. Diabetes is frequently relegated to a small corner of one's life. All participants in this phase had poor glycemic control. Integration is minimal in this initial phase.

There are varying degrees of commitment to diabetes management. The major preoccupation is *being normal* – or not different from others – being thought of as normal, and living life as a normal person. During the first interview, Marlene identified 12 things she did that are not required of nondiabetic individuals, but after identifying each she quickly followed up with such statements as "To me it's just like everybody else" or "There's no difference, you know."

During the having diabetes phase, the tendency was to do the necessary self-care tasks and then to get on with life and forget about diabetes for the remainder of the day. The having diabetes phase was found to last for three years or more. Three participants were in this phase after having diabetes for seven years or longer.

One begins to have increased self-awareness of the body in this first phase, but it is a more passive awareness than is characteristic of the later phases. Two passive metaphors seemed to impede movement beyond this initial phase, and also to move the focus to being normal or not different. *Fitting in* was Bridget's concern, and diabetes just did not fit in with her desired lifestyle. This metaphor was clearly identified in her response to the question about where she would ideally like to be on the graph she had drawn of diabetes stability versus diabetes flexibility:

I can still fit with the group per se. The whole fitting in process is very important to me ... acceptance is a very, very high priority.

Kathleen's passive metaphor *going along with* promoted continuation in this phase. Going along with the suggestions or plans of others

characterized Kathleen's relationships in both diabetes-related and other aspects of her life: "I had no idea of the word [diabetes] and so therefore I just simply went along with everything." During her last interview, Kathleen described a recent incident whereby she skipped her breakfast even though she had taken her insulin, because her daughter was in a hurry to leave for their weekend at the cottage. Kathleen decided to go along with this despite the knowledge that to do so would most definitely put her at risk of hypoglycemia. The two passive metaphors *fitting in* and *going along with* were part of being normal; they encouraged the person to continue in this phase and discouraged the transfer of ownership from the health professional to the person with diabetes.

Phase Two: The Turning Point

The first four participants were in the science of one phase, so initial understanding of the turning point phase was based on their memories of this period. Later, Kathleen was recruited. She was at the turning point when first interviewed but had reverted back to the having diabetes phase by the end of the study. Kathleen's experience demonstrates that individuals in the turning point phase can either return to the first phase or go on to the science of one phase.

The having diabetes phase ends when some event breaks through the seeming complacency of this phase. No longer can diabetes be ignored, diminished, or denied. Sometimes the precipitating event was a physiological one such as having several hypoglycemic reactions or an episode of ketoacidosis. With others, it was referral to a diabetes specialist who started making intrusive changes in the regimen or helped the participant gain an increased understanding of their diabetes. At this point, the person with diabetes is forced to reassess and rethink life with diabetes. Diabetes becomes much more of a focus. The result is an interest in learning about diabetes and total involvement with self-care, which brings with it a sense of confidence and power. Individuals who remained in the having diabetes phase described experiencing events that had stimulated others to move into the turning point but that had not promoted a turning point in their situations.

Mike identified his turning point: "The thing that got me really interested...was the fact that I had all these reactions. Because no one, nobody, ever told me anything about reactions." Matthew said,

It was about three years, when I first started to see Dr. A., that I was glad and I began to understand how to keep it [blood glucose] down

as well... But as soon as I started to do that, as soon as I started to take better care of myself, the benefits were obvious.

Kathleen was in the turning point phase for over a year. It was prompted by her agreement to go on an intensive insulin regimen at the request of her endocrinologist. Kathleen found that this regimen made her continually hungry and made her think much more about her diet as well as other aspects of her regimen, such as more frequent blood tests and insulin injections. Later in the study, her youngest daughter moved out. Kathleen had depended on her daughter for assistance during her night-time hypoglycemic reactions. On the researcher's last visit, Kathleen had switched back to her previous insulin regimen because she could not cope with the new regimen. It made her think too much about her diabetes and she was not prepared to make the required changes. Kathleen validated that she was in the having diabetes phase when the researcher showed her the three phases of integration and asked her which phase she was in.

Phase Three: The Science of One

The third phase occurs as a gradual progression out of the turning point. It was termed the *science of one* because it involves the ongoing, incremental process of building a unique, personalized, and exact science of living with diabetes. The focus continues to be on living (psychosocial emphasis), but not to the detriment of the diabetes (physiological status). Participants in this phase were in good glycemic control.

During this phase, individuals develop a deep understanding of their own diabetes. Often, professional advice is found to be unhelpful, inaccurate, or unfeasible, given the real world with its variety of multifaceted situations (Hernandez, 1991). Since there is no recognized source of accurate information, the person with diabetes learns to *tune in* to his or her own body, responding appropriately to body cues and sensations experienced through this heightened sensitivity. Matthew spoke of the *tuning in* process:

You can become very aware of what your body needs and how it works...you know what your body demands at certain times... you become very focused on paying attention to it.

In her diabetes paper, Ahuva provided a clear description of *tuning in*:

When we go for a hike we carry lots of emergency rations and every so often I will stop and get in touch with my body. It is likely to be sending me some little signal and I have to get used to knowing what they are.

This phase involves active self-experimentation in which life and living become a laboratory for the development of a science of one, a way of living with diabetes that allows persons with diabetes to focus on living their lives, rather than on their diabetes. Diabetes becomes an integral part of them, not an external matter to be taken care of perfunctorily before they get on with the business of living. Debbie illustrated:

The injections are nothing to me, to give them is nothing. Because I've done it for quite a long time so I'm used to that. You know, it does become a routine, a part of your life. It becomes, in some way, you. You are it, it is you. You know? You fit – hopefully you can fit it together, your life and the diabetes.

Quotes from Erica's journal and interview show the extent to which integration can occur:

I decide what I'll eat, and in view of this and my blood sugar, I decide about my insulin. This all happens so quickly and so easily/readily I hardly think of it as "thinking" about my diabetes.

Where I'm at in my experience with it [diabetes] now is that I don't probably separate it out as an experience that I define in and of itself. It's just part of my everyday living. It's just integrated into my living. I can't really separate it out right now.

The tuning in process is just one of several *lifeways*, the "characteristic patterns of thought or action used without conscious knowledge" (Hernandez, 1991, p. 99) that facilitate integration of the *diabetic* and *personal* selves during the science of one phase. These strategies could be either physical, emotional, or cognitive, but they all served to promote integration of the two selves. The particular lifeways that characterized any one individual were consistent with his or her *metaphor of integration*. In fact the metaphor of integration acted as an overarching or all-encompassing lifeway, tying all of the lifeways together.

Many used *exercise* as a physical lifeway, for enjoyment, positive feelings, and flexibility in lifestyle, and to lower blood glucose. In Laura's case, exercise was a part of her *personal* self that she enjoyed and wanted to continue; she found it had benefits for her *diabetic* self:

I have very strong feelings about diabetes and exercise. I feel they go hand in hand. I have an exercise bicycle which I ride ten miles a day.... It's kind of my own time to relax and read. I always feel good after exercising. A day does not go by that I haven't ridden my street bicycle or my exercise bicycle. I have always been sports oriented and enjoyed exercising and now I make a point of it.

Constant thinking, a cognitive lifeway, is illustrated by Sandra's comment:

I live with my diabetes and I sort of like having it. I like who I am and I like what I do. And I don't mind it at all, and I do think about diabetes all the time during the day.

The overall result of these lifeways is the melding of the diabetic self and the personal self, so that they become inseparably unified. Living involves a combination of diabetic and personal factors, but these are not separated out in the person's thoughts or actions. Rather, they have been integrated into a new and complex self.

Four metaphors emerged from the data of those in the science of one phase: diabetes as work, learning to live with diabetes, focusing on feelings, and juggling for control. These metaphors appeared to form the overarching lifeway, reflecting the participants' orientation to their diabetes and promoting integration of the personal and the diabetic selves. In some instances these metaphors were reflective of the participants' attitude to life in general, even prior to their diagnosis.

The most common metaphor was *diabetes as work*. Sandra strove to keep her blood sugar in the normal range, although this was hard work because of her diagnosis of brittle diabetes. She calculated her insulin dosage and her diet using subjective and objective sources of information, and she worked in as much physical activity as she wanted. "It's a challenge to work, work with diabetes and find out more about it," Sandra explained. Richard's interviews and journal reflected several types of work: balancing work with his blood glucose, planning work, calculated risk-taking work, exercise work, and collaborative work with his diabetes educators.

Laura's metaphor was *learning to live with diabetes*:

I have my high blood sugars and my lows, but these are part of my being diabetic and I have learned to live with them. It's knowing your body and how it reacts to highs and lows and knowing what to do which I have learned, and to take it all in stride.

Matthew was *focusing on feelings*, both physical and emotional. He commented, "The only yardstick I use to measure my diabetes is really my blood sugar and how I feel, but I tie these two together." A journal excerpt exemplifies this metaphor:

Decided I needed some exercise before going to bed, or b.s. [blood sugar] would be high in the morning... thought that it must look/ seem strange to roommates that I was exercising so late at night, but keeping blood sugar low, at a comfortable level, worth it.

The final metaphor was *juggling for control*. Mike described juggling diabetes factors along with other life factors. However, because these factors cannot be totally separated the juggling is challenging and very difficult: "Normally the things that are a part of diabetes control are controllable. It's the other things that you can't control and when those go wrong that's when the other [diabetes] ones are affected because they are joined in a way."

Because those in the science of one phase had become experts in their own diabetes – by tuning in to their bodies, experimenting, and learning experientially – they were impatient with educators who tried to tell them what they should and should not do. These participants stated that educators who do not have diabetes cannot truly understand what it is like to have it. Participants believed educators should work collaboratively with them, because they have particular knowledge about their own diabetes while health professionals have general, scientific knowledge about diabetes that might not apply in their case. The researcher used the term *collaborative alliance* to describe this desired relationship.

Discussion

The theory of integration represents a view of diabetes that differs from the adherence perspective characteristic of conventional diabetes education and treatment. Integration theory describes the ongoing integration of selected aspects of diabetes and the diabetes regimen into the life and lifestyle of the individual, while maintaining a focus on the art of living. This is accomplished through heightened self-awareness of the body, various lifeways, a deep understanding of one's own diabetes, and taking ownership of one's diabetes. The content and style of living that resulted from this process often deviated substantially from the guidelines, rules, and regulations that would make up the diabetes regimen established by a diabetes educator. Yet diabetes educators would consider those in the science of one phase in "good" glycemic control. This finding is in direct conflict with the conventional belief that adherence is necessary for good control of diabetes (Alogna, 1980; Becker & Janz, 1985; Cohen et al., 1994; Geller & Butler, 1981; Jenny, 1984; Rosenstock, 1985; Tillotson & Smith, 1996).

Research findings consistently note that a client's view of a health issue differs from the prevailing scientific or medical views (Cohen et al., 1994; Corbin & Strauss, 1988; Jeffrey, 1989; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978; Nichol, 1990; Roberts, 1982). Kleinman and others (Kleinman et al.) differentiate the physician's preoccupation

with the *disease* (focus on biology and psychophysiology) from the patient's concern with *illness* (personal, interpersonal, and cultural reactions to discomfort). Anglo-Canadian and Chinese adults with diabetes stated they were able to obtain help from health professionals with the physical aspects of illness but were alone in dealing with the psychological impact (Anderson, 1990). Corbin and Strauss (p. 169) conclude that the medical focus on adherence is excessively physiological and obscures the complex actions required to meet its prescriptions. Nichol (p. 95) determines that adherence is negative because it encourages obedience to the health professional rather than observation and exploration of personal experience and discovery of alternative practices that could promote individual health. Non-adherence or "cheating" has been viewed as potentially positive, because it involves experiential learning (Maclean & Oram, 1988). In this study, participants in the science of one phase were focused on the psychosocial aspect but not to the detriment of physiological status.

Other researchers have found that chronic illness is not a static event but a continuous trajectory. In research with children and adolescents, Quint (1969) found that diabetes is not an event, but rather a "process of becoming diabetic," of merging role identity. Corbin and Strauss (1988) describe the process of reconstituting identity in which some aspects of the self are retained. They indicate that the chronic illness can be either discounted, kept separate from the rest of the biography (similar to the having diabetes phase in the present study), well integrated, so that the illness and its associated work "is me" (similar to the science of one phase), or somewhere in between.

Strauss and Glaser (1975, p. 58) describe a normalizing strategy – to live as normally as possible despite the chronic illness – as the chief business of the individual who is chronically ill. This responsibility for normalization becomes that of the parents when a child has diabetes (Quint Benoliel, 1975). This normalizing strategy is similar to the focus on being normal that is characteristic of the having diabetes phase of the theory of integration.

Recent qualitative studies of clients with diabetes share some findings with this study. Quint (1969) identified reluctance on the part of subjects to divulge the fact that they had diabetes; she found openness in children but secrecy in adolescents. In contrast, this present study found secrecy to be a reflection not of age but of phase – with increasing openness characterizing later phases of integration. Other researchers studying self-management of diabetes describe a body-listening or

tuning-in process (Price, 1993), self-care decision-making (Paterson & Sloan, 1994), and processes by which clients make changes to a prescribed regimen when it does not work for them (Oram, 1992; Price). Other researchers acknowledge the expertise that clients and families with children develop through experiential or trial-and-error learning (Maclean & Oram, 1988; Paterson & Sloan; Quint), and recommend partnership or collaborative relationships with clients who have diabetes (Paterson & Sloan; Ternulf Nyhlin, 1990) or chronic illness (Thorne & Robinson, 1989).

There are further differences between the findings of the present study and those of other researchers. Quint (1969) found that the physician, not the client, was viewed as the source of expert knowledge, whereas the present study found that in the later phases of the process the client had expert knowledge of his or her particular diabetes.

A well-constructed grounded theory will meet four criteria: fit, work, relevance, and modifiability (Glaser, 1978, 1992; Glaser & Strauss, 1967). The theory of integration has demonstrated *fit* in the eyes of the participants, others with diabetes, and other researchers. This theory *works* because it is able to explain the major variations in those who are living with diabetes. According to Glaser (1992), if a grounded theory both fits and works, then it has achieved *relevance*. The theory of integration was shown to be modifiable as new data presented.

The assumption of common experience of a three-phase process of integration in those with IDDM may not be justified by documenting the integration process in 12 people. However, the trustworthiness of this process is inferred through Lincoln and Guba's (1985) criteria of *credibility* (internal validity), *transferability* (external validity), and *dependability* (reliability). Credibility was promoted through prolonged engagement with participants, triangulation of data-collection methods (interviews, diabetes papers, journals), and member checks (checking data and interpretations with participants). Transferability is ensured when the research provides "the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility" (Lincoln & Guba, p. 316). When these research findings are presented, clients indicate that this three-phase process fits their experience. Dependability was demonstrated with the data from the last three participants. Another researcher arriving at similar or comparable conclusions, given the data, perspective, and situation, can constitute evidence of dependability (Sandelowski, 1986). The results of an analysis, conducted by a

Master of Nursing student, of the data from the last three participants was comparable with those of the researcher. Other studies cited above provide additional evidence of the *tuning in* process and the development of client expertise through experiential learning.

Future research should include the participation of clients with non-insulin dependent diabetes or other chronic illnesses, to see whether they experience a similar integration process. If they do, then it is essential that changes be made in how clients with chronic illnesses are taught. For example, participants in this study saw themselves as diabetes experts. Those in the science of one phase had taken ownership of their diabetes and saw themselves on an equal footing with health professionals. They acknowledged that health professionals had a great deal of general knowledge about diabetes but were equally aware that they were experts in their own particular diabetes. They avoided encounters with nurses and other health professionals who might try to manipulate them or treat them in a pejorative manner. Traditional, adherence-based relationships will be unproductive in meeting desired health outcomes in those who have reached this level of integration.

The results of this study support the need for a change in client/educator relationships toward collaborative alliance relationships. This new role will have ramifications for educational strategies and the type and use of educational materials. Educators need to learn from their diabetic clients, in order to inform their practice, and to seek guidance about what roles would most benefit individual clients (Hernandez, 1995b).

This study provides an alternative understanding of how diabetes is perceived and incorporated into the lives and lifestyles of those who have it, and it challenges educators to re-examine current practices and learn to work collaboratively with their clients.

References

- Alogna, M. (1980). Perception of severity of disease and health locus of control in compliant and noncompliant diabetic patients. *Diabetes Care*, 3, 533-534.
- American Diabetes Association. (1996). *Diabetes facts*. [Brochure]. Alexandria, VA: Author.
- Anderson, J.M. (1990). Home care management in chronic illness and the self-care movement: An analysis of ideologies and economic processes influencing policy decisions. *Advances in Nursing Science*, 12(2), 71-83.

- Anderson, R.M., Fitzgerald, J.T., & Oh, M.S. (1993). The relationship between diabetes-related attitudes and patients' self-reported adherence. *Diabetes Educator*, 19, 287-292.
- Becker, M.H., & Janz, N.K. (1985). The health belief model applied to understanding diabetes regimen compliance. *Diabetes Educator*, 11(1), 41-47.
- Brown, S.A. (1990). Studies of educational interventions and outcomes in diabetic adults: A meta-analysis revisited. *Patient Education and Counselling*, 16, 189-215.
- Cahill, G.F. (1985). Current concepts of diabetes mellitus. In A. Marble, L.P. Krall, R.F. Bradley, A.R. Christlieb, & J.S. Soeldner (Eds.), *Joslin's diabetes mellitus*, 12th ed. (pp. 1-11). Philadelphia: Lea & Febiger.
- Cohen, M.Z., Tripp-Reimer, T., Smith, C., Sorofman, B., & Lively, S. (1994). Explanatory models of diabetes: Patient practitioner variation. *Social Science and Medicine*, 38, 59-66.
- Corbin, J.M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Diabetes Control & Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 329, 977-986.
- Etzwiler, D.D. (1984). Diabetes education: The reason for its existence. *Diabetes Educator*, 10 (Special Issue), 15-18.
- Expert Committee of the Canadian Diabetes Advisory Board. (1992). Clinical practice guidelines for treatment of diabetes mellitus. *Canadian Medical Association Journal*, 147, 697-712.
- Feste, C. (1992). A practical look at patient empowerment. *Diabetes Care*, 15, 922-925.
- Funnell, M.M., Anderson, R.M., Arnold, M.S., Barr, P.A., Donnelly, M., Johnson, P.D., Taylor-Moon, D., & White, N.H. (1991). Empowerment: An idea whose time has come in diabetes education. *Diabetes Educator*, 17, 27-41.
- Geller, J., & Butler, K. (1981). Study of educational deficits as the cause of hospital admission for diabetes mellitus in a community hospital. *Diabetes Care*, 4, 487-489.
- Glaser, B.G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (1992). *Basics of grounded theory analysis: Emergence vs. forcing*. Mill Valley, CA: Sociology Press.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Glasgow, R.E., McCaul, K.D., & Schafer, L.C. (1987). Self-care behaviors and glycemic control in type I diabetes. *Journal of Chronic Disease*, 40, 399-412.
- Hernandez, C.A. (1991). *The lived experience of type I diabetes: Implications for diabetes education*. Unpublished doctoral dissertation, University of Toronto, Toronto, Ontario.

- Hernandez, C.A. (1994). Collaborative alliance: A practice model whose time has come. *Canadian Journal of Diabetes Care*, 18(4), 6-7.
- Hernandez, C.A. (1995a). The development and testing of an instrument to measure integration in adults with diabetes mellitus. *Canadian Journal of Diabetes Care*, 19(3), 18-26.
- Hernandez, C.A. (1995b). The experience of living with insulin dependent diabetes: Lessons for the diabetes educator. *Diabetes Educator*, 21, 33-37.
- Jeffrey, J.E. (1989). *Predictors of quality of life for adults who have rheumatoid arthritis*. Unpublished doctoral dissertation, Case Western Reserve University, Cleveland, Ohio.
- Jenny, J.L. (1984). A comparison of four age groups' adaptation to diabetes. *Canadian Journal of Public Health*, 75, 237-244.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 251-258.
- Kurtz, S.M. (1990). Adherence to diabetes regimens: Empirical status and clinical applications. *Diabetes Educator*, 16, 50-56.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Maclean, H., & Oram, B. (1988). *Living with diabetes*. Toronto: University of Toronto Press.
- Mazze, R.S. (1986). Diabetes patient education: A health care provider perspective. *Diabetes Educator*, 12, 126-130.
- McCaul, K.D., Glasgow, R.E., & Schafer, L.C. (1987). Diabetes regimen behaviors: Predicting adherence. *Medical Care*, 25, 868-881.
- Nichol, H. (1990). *Depersonalization: A semiotic reading of women's discussions on diabetes management*. Unpublished master's thesis, University of Toronto, Toronto, Ontario.
- Oram, B.J. (1992). *The personal meaning of chronic illness within the context of everyday life: A case study of the experiences of people with insulin-dependent diabetes*. Unpublished doctoral dissertation, University of Toronto, Toronto, Ontario.
- Paterson, B., & Sloan, J. (1994). A phenomenological study of the decision-making experience of individuals with long-standing diabetes. *Canadian Journal of Diabetes Care*, 18(4), 10-19.
- Polly, R.K. (1992). Diabetes health beliefs, self-care behaviors, and glycemic control among older adults with non-insulin-dependent diabetes mellitus. *Diabetes Educator*, 18, 321-327.
- Price, M.J. (1993). An experiential model of learning diabetes self-management. *Qualitative Health Research*, 3, 29-54.
- Quint, J.C. (1969). *Becoming diabetic: A study of emerging identity*. Unpublished doctoral dissertation, University of California, San Francisco, California.

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- Quint Benoliel, J. (1975). Childhood diabetes: The commonplace in living becomes uncommon. In A.L. Strauss & B.G. Glaser (Eds.), *Chronic illness and the quality of life* (pp. 89-98). St. Louis: Mosby.
- Roberts, C.S. (1982). Identifying the real patient problems. *Nursing Clinics of North America*, 17(3), 481-489.
- Rosenstock, I.M. (1985). Understanding and enhancing patient compliance with diabetic regimens. *Diabetes Care*, 8, 610-616.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Schlenk, E.A., & Hart, L.K. (1984). Relationship between health locus of control, health value, and social support and compliance of persons with diabetes mellitus. *Diabetes Care*, 7, 566-574.
- Stern, P.N. (1980). Grounded theory methodology: Its uses and processes. *Image*, 12, 20-23.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.
- Strauss, A.L., & Glaser, B.G. (Eds.). (1975). *Chronic illness and the quality of life*. St. Louis: Mosby.
- Ternulf Nyhlin, K. (1990). Diabetic patients facing long-term complications: Coping with uncertainty. *Journal of Advanced Nursing*, 15, 1021-1029.
- Thorne, S.E., & Robinson, C.A. (1989). Guarded alliance: Health care relationships in chronic illness. *Image*, 21, 153-157.
- Tillotson, L.M., & Smith, M.S. (1996). Locus of control, social support, and adherence to the diabetes regimen. *Diabetes Educator*, 22, 133-139.
- Warren-Boulton, E., Auslander, W.F., & Gettinger, J.M. (1982). Understanding diabetes routines: A professional training exercise. *Diabetes Care*, 5, 537-541.
- Welborn, T.A., & Duncan, N. (1980). Diabetic staff simulation of insulin-dependent diabetic life. *Diabetes Care*, 3, 679-681.
- Watkins, J.D., Williams, R.F., Martin, D.A., Hogan, M.D., & Anderson, E. (1967). A study of diabetic patients at home. *American Journal of Public Health*, 57, 452-459.
- Williams, T.R., Martin, D.A., Hogan, M.D., Watkins, J.D., & Ellis, E.V. (1967). The clinical picture of diabetic control, studied in four settings. *American Journal of Public Health*, 57, 441-451.
- Wooldridge, K.L., Wallston, K.A., Graber, A.L., Brown, A.W., & Davidson, P. (1992). The relationship between health beliefs, adherence, and metabolic control of diabetes. *Diabetes Educator*, 18, 495-500.

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